

APRIL - COMMERCIAL ORGANISATIONS

Biobank data breach update

We provided an update on a recent article on the Biobank data breach and noted the differences of the Biobank in comparison to SDEs. PAG members discussed the article's impact on public perception, that while the breach is concerning, public reaction is based on misleading headlines rather than the article's content.

They emphasised the need to strengthen messaging on the differences between Biobank's and SDEs governance and security structures. It was also highlighted by PAG members that "no digital system is completely hack-proof" and suggested learning from past breaches to enhance security measures of SDEs.

Commercial organisations

This was an introductory session to working with commercial organisations as customers. Other ways of working with commercial organisations were also briefly outlined, these are:

- Suppliers providing goods and services
- Partners in a non-financial partnership

PAG members agreed that commercial organisations are profit-driven entities that sell products or services. Members listed what commercial organisations are below:

- Something profit-driven
- Retail
- Supermarkets
- Not public sector
- Profit organisations
- Provides produce for profit

Why they use health data

- To understand real-world evidence
- Test whether existing medicines could be used in new ways
- Support research that could improve diagnosis, treatment and care

How decisions are made

It was noted that all requests go through strict approval processes, these are:

- Data Access Committees (DACs) review every request
- Projects must show clear public and health benefit, not just profit
- Strong checks ensure data is used safely, fairly and responsibly

Strong protections that are put in place:

- Only essential data is shared
- SDEs have no identifiable data leaving the environment
- Legal contract agreements
- Public data use register

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Commercial organisations are charged in a way that:

- Reflects the value of data being used
- Helps support long-term sustainability of the NHS and SDE
- Revenue-sharing model will help to mitigate risks of commercial organisations incorporating data access costs to their products, leading to higher charges for the NHS later. The revenue-sharing model ensures the NHS benefits from commercial success.

Questions raised by PAG members:

How do patients benefit as individuals?

- Clear reporting back to the public
- Exploring direct patient benefits, for example; trial access, free access to new drugs or research donations.

Are there any preferences for particular types of research?

- Weight management
- Obesity
- Heart disease
- Cancer

Benefits:

- Faster innovation in medicine and clinical trials
- Potential for better local health outcomes
- Opportunities for jobs and research interest

Risks:

- Public trust if partnerships are not explained clearly
- Concerns linked to potential data controversies
- Re-identification fears and reputational damage to Yorkshire & Humber Secure Data Environment

Transparency:

- Clear public expectations of who is using the data and why
- Sharing real examples of benefits for patients and NHS
- Being clear about red lines/ red flags for partnerships